

7th Annual Report and Financial Statements

of the HSP Research Foundation Inc.

2011/'12



**HSP Research
Foundation**

*A better deal for HSPers, their
children and their grandchildren*

7th ANNUAL REPORT 2011/'12
to members of the HSP Research Foundation Inc.
and the HSP community.

September 2012

The Foundation was created in 2005 to facilitate and fund research to find a cure for Hereditary Spastic Paraplegia (HSP) and also to serve the interests and needs of those with HSP as the hub of the HSP community, creating awareness and providing support and education. This report describes the extent to which we achieved our mission over the 2011/'12 financial year.

Towards a Cure Research Program - Stem Cell Research Project

The stem cell research project *Identifying Therapeutic Drug Candidates for treating HSP* began in January 2011 and is due for completion at the end of 2012. Co-Principal Investigator and Director of the National Centre for Adult Stem Cell Research, Professor Alan Mackay-Sim, provided a progress report in May 2012, saying that the project is progressing on schedule. The progress report and details of the Research Program are available on the website at: <http://www.hspersunite.org.au/stem-cell-research-project-2/>. The Foundation supported the funding of this project again this financial year by way of research grant in the amount of \$100,000.

Much of the recent work has, and will continue focus in two areas - firstly, in the definition and specification of the cellular targets (those significant cell functions impaired in HSP cells) as new findings continue to accumulate; and secondly, in technological advances in measuring and quantifying the differences being found between HSP cells and control cells.

The body of knowledge is continuing to grow regarding cell organelles and how they move and are distributed. New measurement techniques and technologies are being developed and employed to study and quantify these phenomena. Plausible explanations for why HSP symptoms may not develop until well into adulthood are being formulated. Important differences in neuronal HSP stem cells are being described. Common cellular pathways with other motor neuron diseases have been identified.

A class of drug compounds that shows promise in rectifying or compensating for various impairments in HSP stem cells has been identified. Before the end of 2012, it is planned to further screen these compounds against the HSP cell targets and measure the results using the technological and quantification refinements currently in development.

At that point, the timing will be right to consider options and make plans for the next stage of research. One of the possibilities is that the drug compounds identified may be tested for safety and efficacy in an animal model of HSP as a first step in preclinical trials. The researchers have secured funding from the National Health & Medical Research Council to cover their salaries for the next 3 years. This will allow the Foundation to more easily and flexibly provide funding for operational costs of the research such as consumables required for drug screening or the development and maintenance of laboratory animals for drug testing.

Gene Testing

All Australians at risk of HSP can avail themselves of the testing and screening service for SPG4, SPG3A and SPG31. Information is available on the website at: <http://www.hspersunite.org.au/genes-hsp/gene-testing-service/>. For those who test negative to the three gene tests offered, but who almost certainly have HSP and would like to know for purposes such as family planning, there is no easy answer at this point.

Scientific and technical advances in gene testing still continue at a hectic pace. Affordable mapping of an individual's exome will soon be available, and will be the preferred gene testing option. To that end, earlier in 2012, the Foundation gave a \$10,000 research grant to the Anzac Research Institute for the development of software to screen for all known HSP gene mutations from an individual's whole exome map. A pilot study is currently underway, with a view to having much greater testing coverage of the HSP gene universe available to all Australians at risk of HSP in the foreseeable future.

HSPers thinking of getting tested are strongly encouraged to see a genetic counsellor first. One of the issues you can explore with your counsellor is the feasibility of getting tested as an outpatient in a public hospital. In some cases, this may significantly reduce or even eliminate out of pocket expenditure. Health card holders pay nothing.

Management & Treatment

There is much that HSPers can do to mitigate and alleviate symptoms. Physical fitness, especially strength and flexibility, can make a significant difference in the quality of life experience with HSP. One of the best investments that HSPers can make is to see a neurophysiotherapist, or a physiotherapist whose practice focuses on neurological conditions and their rehabilitation, for assessment, treatment and the development of a custom-designed, self-managed exercise program that should be done regularly and indefinitely.

There is little research globally into the management and treatment of HSP specifically, however we are fortunate in Australia to have 2 HSP gait studies underway concurrently, one for adults and one for children, both located in Victoria. The adult study is a retrospective one, involving an analysis of HSP gait patterns of around 40 adults who have had a gait assessment through the Southern Health Clinical Gait Analysis Service. The gait study of children with HSP is the focus of a Ph.D. study at the University of Melbourne by physiotherapist Brooke Adair. The Foundation supported this work with travel grants totalling \$5,000 for children with HSP and their parents to be able to travel to Melbourne to participate in the study. We eagerly look forward to the findings of both studies in due course.

Awareness, Education & Support... Developing the HSP Community

Education & Support

Mobility maintenance and management is a major concern for HSPers. Relevant issues and medical professionals concerned include neurology, rehabilitation, orthopaedics, spasticity and pain management and treatment, specialised therapies including physiotherapy, neurophysiotherapy, podiatry / orthotics and occupational therapy. The Foundation provides regular, ongoing information on fitness, self-managed exercise programs, assistive technologies, lifestyle and quality of life issues such as incontinence. Other topics covered include genetics,

family planning and mental health. Information and education media include the Foundation website, e-mail and phone inquiries, and workshops.

The website is a significant resource and library/archive. Web statistics continue to consistently show that a monthly average of around 800 people from 70 countries view about 4,000 pages on the site. About 50% of the site traffic is international, mainly from the US (20%), the UK and Germany (8% each). A listing of community recommended medical practitioners is on the website with the ability to be added to at any time.

There is a steady stream of inquiries to the Foundation (including from medical practitioners) seeking information mostly related to gene testing, family planning, mobility management, finding a suitable neurologist or physiotherapist, and spasticity management. Each and every inquiry, whether from Australia or overseas receives a timely, personal response.

An HSP Workshop was held at the City East campus of the University of South Australia in Adelaide in November 2011, and was judged a worthwhile effort, both in educational and in social terms, by all concerned - participants, presenters and organisers. Special thanks to Dr. Susan Hillier Ph.D. of the University's School of Health Science for generously providing the venue and for vital support on the day. Workshops have now been held in Melbourne, Sydney, Brisbane and Adelaide over the past few years. No other locations in Australia have more than 10 members of the HSP community within comfortable travelling distance. Based on this reality, based on human resource limitations, and also the desire for more equity for community members in learning opportunities, it has been decided to discontinue holding annual workshops. There is clear potential for broad-based educational opportunities via on-line seminars (webinars), whether provided by the Foundation or some other body, and these may be developed as resources and priorities allow.

Awareness

The Foundation had a presence at this year's Rare Disease Day on 29 February. Linked with and following from this initiative, we advocated community participation through petition signing and attendance at nationwide gatherings in support of the National Disability Insurance Scheme, and continue to keep the community informed of political developments and decisions regarding the scheme.

Growing & Developing the Community

At the end of the financial year, the HSP community numbered 478 members as recorded in our Contacts Management System, up from roughly 400 this time last year... an increase of 20% year-on-year. Given the issues with HSP diagnosis, and the limitations of current gene testing, the best estimate is that about 220, or almost half the community, have HSP, with the remainder comprising family, friends and supporters. Based on the estimate that there are around 1,700 HSPers in Australia, we still have a long way to go to reach out and support everyone who can benefit from joining the HSP community. Given our small size, it is important to continue the focus on growing the community with the aim of achieving critical mass and sustainability, thus ensuring continuing support, funding, the ability to take on initiatives, to provide a source of volunteer support for the work of the Foundation, and to have sufficient HSPers for clinical drug trials in the future. For reasons best known to themselves, we know of several instances where HSP families are aware of our existence, even to the extent of making inquiries of us for information relating to HSP, yet choose not to become community members. This is demotivating to say the least.

Connecting with each other

There is an ongoing need for more connection between community members. The bulk of communications will necessarily remain electronic with the website and e-mail being the main methods. Given that HSP is a rare disease and Australia is a big country, it is a huge challenge to create opportunities for personal interaction. We encourage people to initiate social contact with community members who may live near them, and we can offer support to help make that happen. Anyone who is interested just needs to let us know by e-mail and we can circulate their contact information to community members near them with a view to forming a social group. The Community Contact Initiative was not implemented this year as there was no one available to provide the management and leadership required.

54 people from Australia with HSP are now shown on the global database <<http://freyerse.org>> up from 42 a year ago. The visual interface is a global map on the website, and this can be magnified to local level so that people can see who in the community lives near them and make contact with them. It also allows information to be shared and friendships to develop at a distance.

Global Collaboration

With just half a million people globally estimated to have HSP, and only a handful of support groups such as this Foundation in existence, there is a compelling need to open and continually develop lines of ongoing communication and dialogue with our international colleagues in the mutual best interests of everyone with HSP everywhere. Medical researchers tend to be discipline-based and work on a number of diseases simultaneously. Therefore the onus for ensuring that the interests of people with HSP are being well served rests squarely with the support groups. Support groups can play an important role in helping set research priorities; in providing funding for research; in facilitating ongoing dialogue between researchers in the interests of leverage and synergy, and in the avoidance of duplication; in advocacy, public awareness, community development and social action, especially in concert with support groups for other conditions who share similar social and political agendas.

Foundation Operations

Communications

Electronic communications: 89% of the community have provided us with an e-mail address. We utilise e-mail communications with community members where possible, with postal mail being a backup for those without e-mail. However postal mail recipients do not receive quarterly updates and certain other communications that are only transmitted electronically due to the time, human resources required and expense. Everyone is encouraged to provide us with an e-mail address, and for those community members for whom e-mail is not feasible, we encourage them to explore the possibility of receiving e-mails via family or friends. Another way is to access our website regularly at the local library, where assistance is often available for those who require it.

Developing our Capability & Capacity

The ongoing challenge of every small non-profit, us included, is how to be effective and businesslike so that scant resources can be well employed given that we are run totally by volunteers. We are maintaining and continuously improving systems and processes to service the handling and processing of general inquiries, requests for medical and technical information on

HSP, correspondence, initiatives such as the fundraising campaigns and donation processing and receipting.

We continue to have way more jobs and projects than people to do them professionally. This human resource shortage is far and away the critical limitation regarding what the Foundation can be and can achieve. At the start of the year we again tried to find people with professional expertise who were available to take on projects and roles for the Foundation, sadly without success.

We are enormously grateful for the continuing support of a few key people. Our heartfelt thanks to Isaac Nakhla, our dedicated Web designer and technician, for his maintenance and improvement of the website. Also to Ryan Keating who continues to support the development of the Contacts Management System. Both Ryan and Isaac have no connection with HSP, but they each have a keen sense of contributing to society and selflessly doing good. Both these young men also volunteer their valuable time, knowledge and expertise for other charities. Margaret Flood provides invaluable support through her dedicated management of the Contacts Management System. Finally, my thanks to fellow committee members of 2011/12 – Robin Bligh, Steve Lunn, Ken Price, Chris Hall and Tim Xiros for their continued efforts in the interests of the Foundation.

Fundraising

'Give Generously' Campaigns

The Christmas campaign in 2011 yielded \$9,000, 12.5% up on the figure for December 2010. The June campaign this year amounted to \$43,626, 12% up on last year and 13% down on June 2010. This campaign is designed to coincide with the end of the tax year so that people can claim immediate deductions for their charitable contributions to the Foundation.

Events

Event fundraising through sponsorship by supporters continues to be a significant source of Foundation income, with people entering the Cole Classic swim and the City 2 Surf events in 2012, both Sydney-based, to raise funds for HSP research. In total, event fundraising amounted to just over \$10,000, 30% down on last year, but still a significant 8.5% of our fundraising target for 2012. Events are also important as we see HSPers doing extraordinary things, and this is good for us all. Sponsorships come largely from outside the community via participants' families and relatives, friends, colleagues and community. Events provide a rare chance to get some publicity and raise awareness of HSP and HSPers.

Philanthropic Grants

Several high-quality applications to carefully chosen philanthropic organisations and grant makers were submitted over the past year, and fortunately, this is reflected in our results. We received the second of two \$30,000 grants from the Ronald Geoffrey Arnott Foundation, managed by Perpetual, and \$15,000 from the Flack Trust, a 50% increase on last year's grant. We are sincerely grateful for this vital support from both these philanthropic organisations.

Who Gives?

One of the larger challenges we face is expanding the base of contributors to the Foundation. There are two main sources of contributors:

1. 'Inner Circle' – this is how we describe people in the HSP community / Foundation members. 20% of community members contributed over the financial year, a pleasing increase from the 15% last year. However the reality is that fully 80% of community members give nothing. The significant challenge to engage this 80% is necessary, not just because it will mean more funds, but because it will reflect an informed community with a willing spirit, no matter how much they are able to give.
2. 'Outer Circle' – this is how we describe people who are supporters or potential supporters but have not joined the HSP community. This includes people in the extended family, relatives, friends, colleagues, and in the communities in which HSPers live. Over the 2011/12 financial year, just under 200 people in this outer circle contributed financially, mainly as sponsorship of event participants, but also in lieu of birthday presents for a milestone birthday of a community member. We have barely scratched the surface with potential fund-raising initiatives instigated by community members with this outer circle. The challenge is to encourage community members to fundraise on behalf of the Foundation. Whether it is a barbecue or a birthday, trivia night or cake bake or something more adventurous – we all need to be thinking about ways to engage the broader community in contributing to the cause. There may also be publicity/awareness opportunities with these sorts of activities as well. The other advantage of the outer circle is that the potential and limits are much greater in terms of who we can reach and the funding we can raise.

Summary

We continue to be proud that over 95% of all money raised goes to fund research, and also proud that this can happen only because we are a 100% volunteer organisation. Last calendar year we raised a total of \$111,918. This year's target was set at \$120,000 with \$96,706 already raised. It is unlikely that we will reach this target in 2012 based on Christmas giving figures over the last 2 years, however we will likely top \$100,000 for the year, and that is a significant achievement.

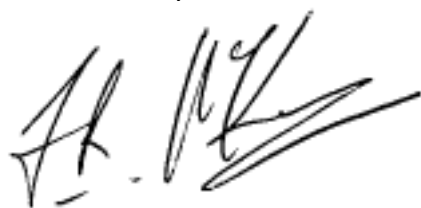
Financial Statements

A Summary of the Audited Financial Report of the Foundation for the 2011/12 financial year follows on the next two pages. We have the capacity to meet our current and foreseeable commitments including research funding and are confident of our continuing financial good standing into the future.

Comments or Feedback

I submit this Annual Report to you, the members of the HSP community and the Foundation, in good faith and with optimism and confidence that we are currently fulfilling our mission and achieving worthwhile goals, and have a high expectation of continuing that into the future. I welcome any comments or feedback, thoughts or ideas, or questions that you may wish to ask. E-mail me at frank@hspersunite.org.au.

Yours Sincerely,



Frank McKeown
President

HSP RESEARCH FOUNDATION INCORPORATED
ABN 46 648 875 912

SUMMARY OF AUDITED FINANCIAL REPORT 2012

PROFIT AND LOSS STATEMENT FOR THE YEAR ENDED 30 JUNE 2012

| | 2012 | 2011 |
|--------------------------------------------------------|---------|---------|
| | \$ | \$ |
| INCOME | | |
| Gross Loss Trading | - | - |
| Membership Fees Received | - | - |
| HSP – DGR Donations Received | 130,383 | 95,177 |
| Interest Received | 5,929 | 2,581 |
| Other Income | - | 240 |
| ATO Refunds | 211 | 9,712 |
| | 136,523 | 107,710 |
| EXPENSES | | |
| Accountancy | 623 | 623 |
| Auditors Remuneration – Fees | 1,060 | 1,066 |
| Dues | 396 | 378 |
| Other Expenses | 323 | 85 |
| Postage & Post Box Charges | - | 60 |
| Printing & Stationery | - | 180 |
| Research Expenditure | 110,000 | 50,000 |
| Subscriptions | - | 726 |
| Sponsorship | 600 | - |
| Web Site Development Amortized | 800 | 800 |
| | 113,802 | 53,918 |
| OPERATING PROFIT | 22,721 | 53,792 |
| NON-OPERATING INCOME AND EXPENSES | | |
| Non Operating Expenses | | |
| Less Research Expenditure not yet presented as paid | - | - |
| | 22,721 | 53,792 |
| OPERATING PROFIT BEFORE INCOME TAX | 22,721 | 53,792 |
| OPERATING PROFIT AND EXTRAORDINARY ITEMS | 22,721 | 53,792 |
| Retained Profits at July 1 | 119,758 | 65,966 |
| PROFIT AVAILABLE FOR APPROPRIATION | 142,479 | 119,758 |
| RETAINED PROFITS | 142,479 | 119,758 |

HSP RESEARCH FOUNDATION INCORPORATED
ABN 46 648 875 912

BALANCE SHEET AS AT 30 JUNE 2012

| | 2012 | 2011 |
|---------------------------------|----------------|----------------|
| | \$ | \$ |
| CURRENT ASSETS | | |
| Cash Assets | 142,479 | 118,958 |
| Receivables | - | - |
| TOTAL CURRENT ASSETS | <u>142,479</u> | <u>118,958</u> |
| NON-CURRENT ASSETS | | |
| Intangible Assets | - | 800 |
| TOTAL NON-CURRENT ASSETS | <u>-</u> | <u>800</u> |
| TOTAL ASSETS | <u>142,479</u> | <u>119,758</u> |
| TOTAL LIABILITIES | <u>-</u> | <u>-</u> |
| NET ASSETS | <u>142,479</u> | <u>119,758</u> |
| EQUITY | | |
| Retained Profits | 142,479 | 119,758 |
| TOTAL EQUITY | <u>142,479</u> | <u>119,758</u> |

A full copy of the Audited Financial Report 2012 is available to members on request by emailing admin@hspersunite.org.au (2.3MB PDF file; 12 pages) or by writing to:
HSP Research Foundation
PO Box 4008
Rathmines NSW 2283